

Missing out- report on experiences of students with autism from minority ethnic communities

Corbett, Clare; Perepa, Prithvi

Citation for published version (Harvard):

Corbett, C & Perepa, P 2007, *Missing out- report on experiences of students with autism from minority ethnic communities*. National Autistic Society, London.

[Link to publication on Research at Birmingham portal](#)

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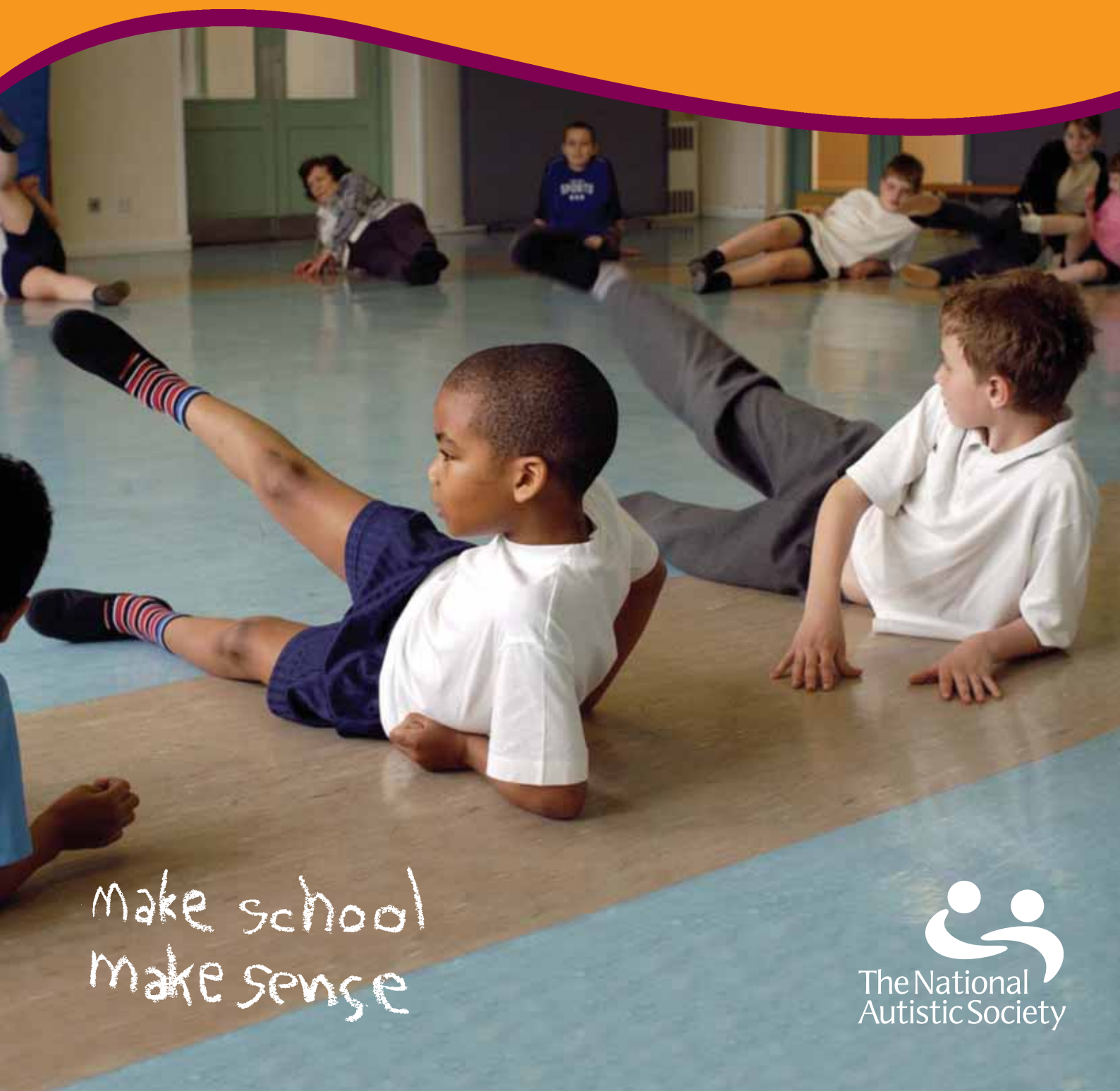
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Missing out?

**Autism, education and ethnicity:
the reality for families today**

Clare Corbett and Prithvi Perepa



make school
make sense

First published 2007 by The National Autistic Society
393 City Road
London
EC1V 1NG
Email: nas@nas.org.uk
www.autism.org.uk

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ISBN 1-905722-27-3 978-1-905722-27-3

Designed by Cottier and Sidaway
Printed by Crowes Complete Print

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Note: the photographs in this report feature young people who attend National Autistic Society schools, not the interviewees whose responses are included throughout the text.

Acknowledgements

The authors would like to thank the families who contributed to the research in this report. We would also like to thank all the staff at The National Autistic Society (NAS) who have worked on the *make school make sense* research and this report, particularly Beth Reid, Melanie Quashie, Francine Brower and Chris Gibbons.

Terminology

The term 'black and minority ethnic' (BME) communities is used in this report to represent anyone who does not come from a White British background. This includes visible minority ethnic communities, including those from mixed backgrounds and those who are not visibly different but who experience disadvantage by virtue of minority status such as gypsies and travellers, asylum-seekers, refugees or new immigrants.

Methodology

In 2006 the NAS carried out the largest ever survey on autism and education in the UK as part of the *make school make sense* campaign. The statistics quoted in this report are taken from respondents who described their child as from a non-White British ethnic background. It is important to bear in mind that as NAS members the experiences of these respondents are probably better than the average because of the support they receive. Additional qualitative data comes from research with parents of children with an autistic spectrum disorder who are from BME groups between September and December 2006 and from qualitative interviews conducted with families from BME communities from June 2004 to July 2005.

What is autism?



Autism¹ is a lifelong developmental disability that affects the way a person communicates and relates to the world around them. The autistic spectrum encompasses children with profound learning disabilities and little or no verbal communication, through to those with average or high IQ, including those with Asperger syndrome. Everyone with the condition shares three main difficulties, known as the 'triad of impairments'.

Social interaction

Difficulty with social relationships ranges from being withdrawn, to appearing aloof and indifferent, to simply not fitting in easily. People with autism may also seem insensitive to the feelings of others. This can lead to problems in the playground, with making friends and, in turn, bullying.

Social communication

Difficulty with verbal and non-verbal communication ranges from difficulties with developing speech, to repetitive or formal use of language. People with autism may also not fully understand gestures, facial expressions or tone of voice. They may also understand instructions and questions literally. Understanding teachers and participating in class can be challenging as a result.

Social imagination

Difficulty in social imagination can impact in understanding how others think and feel and in the development of interpersonal play and imagination. Difficulty in this area may also manifest itself in a resistance to change, so children with autism may find it hard to cope with changes to their timetable, for example. They may also struggle with subjects that use abstract ideas.

¹ Here we use the terms autism and autistic spectrum disorder (ASD) to refer to a group of disorders, including classic autism, Asperger syndrome and high-functioning autism.



Key findings and recommendations

Children with autism from black and minority ethnic (BME) communities experience discrimination on two fronts – their disability and their ethnicity. This isolates them from the education system that should provide opportunities for success. Some excellent practice exists but sadly this is still an exception. The neglect of BME families by researchers, professionals and service providers is unacceptable and must be addressed with urgency.

Issues for BME families

- Evidence about the prevalence of autism in various communities and its impact on family life is inconsistent.
- Communities may not be aware of autism, their rights and relevant services.
- Services that are available do not always meet the needs of these families.

Recommendations

- Local authorities, Primary Care Trusts (PCTs) and Local Health Boards (LHBs) must ensure that generic autism services are accessible to families from all ethnic backgrounds and should help in raising awareness about autistic spectrum disorders (ASDs) and the support available amongst BME communities.
- Research should be commissioned into prevalence rates in different communities, and the impact of culture on the diagnostic process.

The right school for every child

- Only 31% of parents of BME children felt as if they had a choice of school for their child.
- Many parents had to fight to get appropriate education for their children.
- 41% of children from BME groups in our survey had been bullied, and many parents commented on the devastating impact it had on their child.
- 24% of BME children had been excluded from school. In addition, just 22% of parents said that their local authority provided support when the child was excluded. Data on fixed term exclusions for pupils with special educational needs (SEN) in England in 2004-05 reveals substantial variation between different ethnic groups.

Recommendations

- It is essential that local authorities work to ensure that every child with autism has local access to a diverse range of mainstream and specialised educational provision which can meet the child's individual needs.

- Bullying on the basis of disability, race or both must be addressed by better training for school staff and by ensuring that the interests of children with autism from BME backgrounds are explicitly included within schools' anti-bullying policies.
- The Government and Welsh Assembly Government must prioritise analysis of the reasons for differences in exclusion rates between ethnic groups.

The right training for every teacher

- Only 31% of BME families thought that teachers had received the professional training they need to meet the special needs of children with autism.
- BME families rated the quality of training of all professionals in their child's school at least 10% lower than their White British counterparts.

Recommendations

- All professionals working with children with autism from BME communities should receive training in autism as well as cultural awareness to meet the needs of diverse communities.

The right approach in every school

- 28% of parents believe that their children would benefit from speech and language therapy but are not able to access it.
- Parents from BME communities were less satisfied with their child's academic and social progress compared to their White British counterparts.

Recommendations

- Schools and local authorities should monitor the experiences of BME families to assess and address differences in satisfaction levels.
- The Government and Welsh Assembly Government should resource and monitor the implementation of speech and language therapy actions in the *National service framework for children, young people and maternity services* in England and in Wales and ensure that children from BME backgrounds can and do access this support if they need it.
- Speech and language therapists working with children from bilingual or multilingual families need to be aware of strategies to teach communication skills to these children.





make school make sense

Without adequate support and appropriate provision, children with autism can find it difficult to make friends, to participate in class and to integrate into school life. At worst, they are bullied, excluded from school, or both. There are an estimated 11,000 children with autism from black and minority ethnic (BME) backgrounds in England and Wales².

In a recent study, published in the *British Medical Journal*³, researchers found that while the social and economic needs of all families with disabled children are high and remain largely unmet, provision is particularly inadequate for children with an autistic spectrum disorder (ASD) and for disabled children from minority ethnic families. Children with an ASD who are also from a minority ethnic background may miss out on account of their autism and their ethnicity.

"Sometimes I feel doubly discriminated, firstly, because of the disability and then because of our skin colour."⁴

"I really do feel that ethnicity has a significant impact on the level and type of education given to my child. There appeared to be more of a belief that my child was bad as opposed to having special needs...I think that Black children are more than doubly penalised within the education system because their special educational needs causes them to have difficulty accessing appropriate education, because they are Black, and because they are boys. This hinders them in achieving what they should in today's educational system."

In 2006, The National Autistic Society (NAS) carried out the largest ever survey on autism and education in the UK. This provided the evidence base for our *make school make sense* campaign to improve educational provision for children with autism. Our survey showed that local provision is often limited, teachers' training in autism is inadequate and that families have to struggle to access support their children are entitled to. Over 40% of the children in our survey had been bullied at school, and 20% had been excluded from school, often due to teachers' lack of autism awareness. These statistics are shocking, but sadly, the experiences of families who described their child as belonging to a background other than White British were consistently worse than the average.

² This figure is based on applying the current accepted prevalence rate for autism of 1 in 100 to the number of children (aged five to 17) from BME communities according to the 2001 Census.

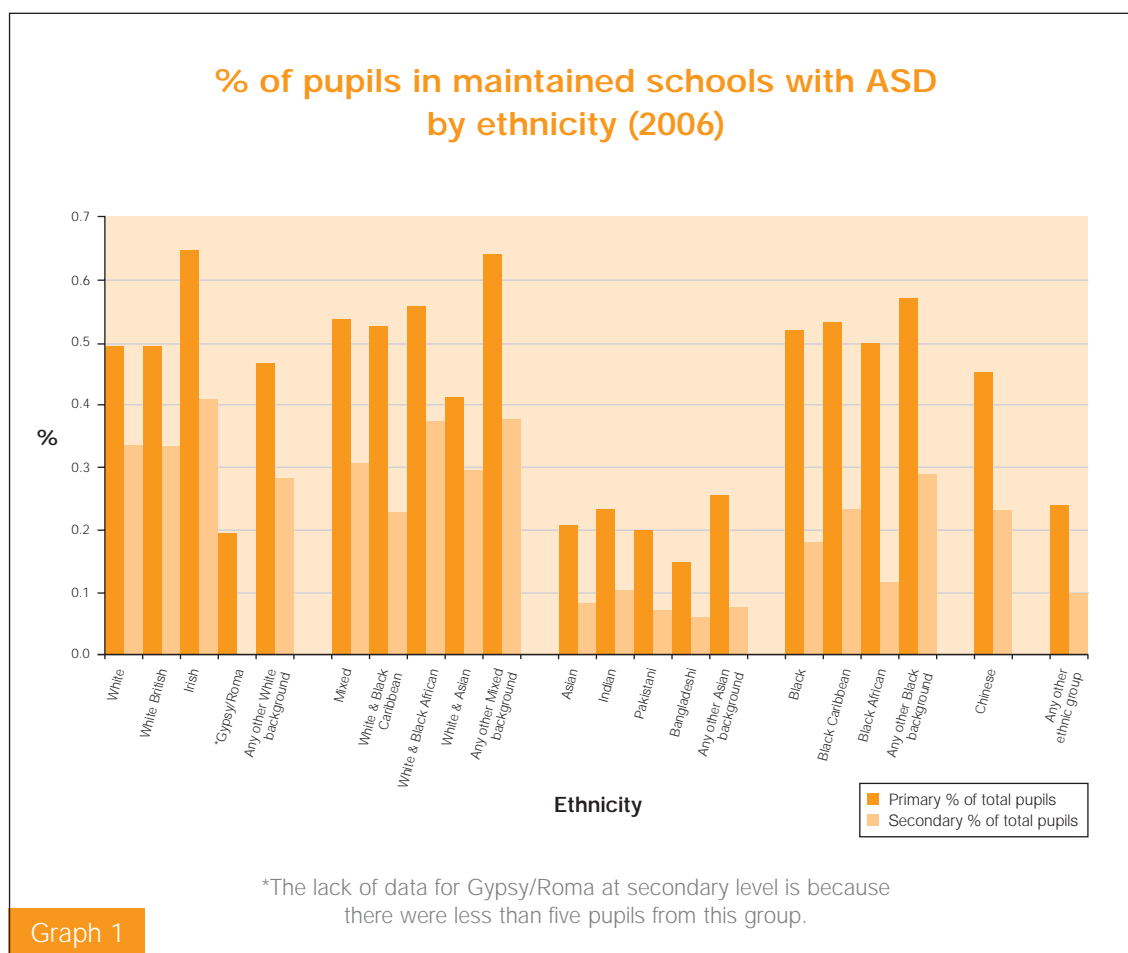
³ Sloper, T. and Beresford, B. (2006). Families with disabled children. *British medical journal*, **333**.

⁴ The quotes in this report are from parents of children with an ASD who are from BME groups. They are taken from surveys conducted by the NAS as part of the *make school make sense* campaign collected between September and December 2006 and from qualitative interviews conducted with families from BME communities from June 2004 to July 2005.

Despite the plethora of research on the prevalence of autism, there has been very little research carried out into the experiences of non-White families and there are almost no specific support services targeting these groups. In this report, we reveal that children with autism from BME families experience disproportionate discrimination and disadvantage. We call on the Government, the Welsh Assembly Government and local authorities to develop culturally specific services, where appropriate, and to ensure that existing assistance at school is accessible to – and supports – children with autism from a BME background.

The numbers debate

The majority of epidemiological studies on autism do not report or analyse data regarding ethnic background, and those that do produce an inconsistent picture of prevalence amongst different ethnic groups. Some reveal a higher incidence of autism⁵, others a reduced incidence⁶ and further studies show no difference at all in incidence among different ethnic populations⁷. The Pupil Level Annual School Censuses (PLASC)⁸ in 2006⁹ (see graph 1) shows substantial variation in the percentage of pupils with an ASD amongst different ethnic groups and between primary and secondary school.



⁵ Goodman, R. and Richards, H. (1995). Child and adolescent psychiatric presentation of second-generation Afro-Caribbean's in Britain, *British journal of psychiatry*, **167**, pp362-369; Dyches, Wilder, Sudweeks, Obiakor and Algozzine (2004). *Journal of autism and developmental disorders*, **34**(2)

⁶ Croen, L. A., Grether, J. K., and Selvin, S. (2002). Descriptive epidemiology of autism in a California population: who is at risk? *Journal of autism and developmental disorders*, **32**(3), pp217-224.

⁷ Fombonne, E. et al. (2001). Prevalence of developmental disorders in the British nationwide survey of child mental health. *Journal of the American academy of child and adolescent psychiatry*, **40**, pp820-827.

⁸ Which identifies the main or 'primary' need of pupils who are supported at school action plus and those pupils with a statement of special educational needs (SEN).

⁹ In response to a parliamentary question from Janet Dean, MP. Number 110589. 1 February 2007.



The reasons for variations in the PLASC data are difficult to ascertain and there are also significant limitations to the data. The small numbers of pupils from certain ethnic groups means that the disability of one or two children may misrepresent prevalence within the community as a whole. The data only takes account of pupils whose main or primary need is an ASD. It therefore excludes children who have multiple needs, which may include an ASD. For example, some children's primary need is a moderate

learning disability (MLD) but they also have an ASD. Furthermore, PLASC only includes data about children who are on School Action Plus¹⁰ or have a statement of special educational needs (SEN). This means that it may miss children with high-functioning autism or Asperger syndrome who do not qualify for School Action Plus or a statement, or children whose parents have not fought for additional support. Additional limitations to the PLASC data and other studies on autism prevalence and ethnicity include variation in the diagnostic criteria and tools used by different professionals and in different areas which can lead to variations in prevalence rates. Problems with the recruitment processes for research studies, which result in fewer BME participants, have also been identified.

It is imperative that the limitations of previous research studies are addressed. Variations in the numbers of pupils with an ASD in different communities, between years and between primary and secondary cohorts must be thoroughly explored. Do they reflect real differences in incidence of ASD between ethnic groups? Are they symptoms of lower rates of diagnosis or children from some communities having other primary needs? Do they relate to issues surrounding the diagnostic process, including lower take-up of health services by some communities? Or are they a result of low cultural awareness of ASD, cultural or linguistic barriers, direct discrimination or a combination of these factors? The PLASC data only recorded ASDs as a separate category from 2004 so it will be interesting to analyse ongoing trends in prevalence. In addition, the Government and Welsh Assembly Government should commission further research into the prevalence of autism amongst minority ethnic groups in England and Wales. Local authorities should also record the number of BME families who access autism support services if they do not already do so.

Perceptions of autism in different communities

Research exploring the experiences of families from BME communities with a child with autism living in the UK or elsewhere has also been neglected. The findings of our Black and Minority Ethnic (BME) Communities Project and information gathered for this report highlight the limited understanding of autism in some minority ethnic communities. They also confirm that autism is perceived differently by different communities and sometimes by different members from the same community. This has an impact on the way both parents and professionals respond to a child with autism from a minority ethnic background. It can mean that access to support is delayed and that children do not receive the level of support they need. There is widespread evidence of the importance of early intervention in improving outcomes

¹⁰ Used within schools to describe the additional support provided to children with SEN.

for children with autism and their families¹¹. Missing out on support at an early age has a significant negative impact on the development of the child as well as an economic impact for the local authority, which may have to provide more complex and expensive support at a later stage.

Some of the developmental milestones used to diagnose ASD are culture-specific. This means that children from BME communities may miss out on a diagnosis or receive a late diagnosis because their families do not recognise differences in their development that are due to an ASD. For example, not making direct eye contact, one of the diagnostic criteria for ASD, is viewed by some people as a sign of respect. In some cultures it is accepted as 'normal' if boys do not develop speech until



three or four years of age, while in others children are expected to start speaking after two years of age. Stigma around disability can be particularly acute in certain minority ethnic groups and this may result in the reluctance of families to seek a diagnosis for their child. Some languages do not have a word for autism and many interpreters substitute terms that mean 'mental health' or 'learning disability', which causes confusion for families. In addition, a lack of early take-up of healthcare and other services among communities for whom English is an additional language and other communities, including travellers, may reduce opportunities for learning about autism and for accessing a timely diagnosis¹².

"When Ope approached his third birthday, one of my friends asked me whether I thought Ope was autistic. I had never heard this word before and so mistook this for artistic."

"Within the African community some believe that having a child with a disability is a generational curse, which is similar to some other cultural communities. I feel that there needs to be more work done with black and minority ethnic communities to help them help themselves. The relevant agencies need to 'own' some of this work." (Parent from the African community)

The cultural specificity of key developmental milestones and social communication indicators can also affect the diagnostic process. As such, when families finally reach diagnosis stage, professionals' lack of cultural awareness can result in an incorrect analysis. The lower numbers of children with autism in certain ethnic groups may be because of difficulties disentangling learning difficulties from issues associated with English as an Additional Language (EAL)¹³ and/or because professionals fail to appreciate the need to make a distinction. If for either of these reasons autism is not identified when it should be, children miss out on the support they need.

¹¹ Smith, V. K. and Dillenbeck, A. (2006). Developing and implementing early intervention plans for children with autism spectrum disorders. *Seminars in speech and language*, 27(1), pp10-20; Turner, L.M. et al (2006). Follow-up of children with autism spectrum disorders from age 2 to age 9. *Autism*, 10(3), pp243-265

¹² Lindsay, G., Pather, S., and Strang, S. (2006). *Special educational needs and ethnicity: issues of over and under representation*. University of Warwick.

¹³ Lindsay, G., Pather, S., and Strang, S. (2006). *Special educational needs and ethnicity: issues of over and under representation*. University of Warwick.

"I feel that within the Asian community disability stands out like a sore thumb and the community tends to feel sorry for the family...our experiences have made me realise that there needs to be some education within the community about the disability. Different services need to invest in this process so that people can get some support from their cultural groups."



The support void

If a family successfully navigates the many barriers already outlined and manages to get a diagnosis for their child, they are often then faced with a support void. The National Autistic Society provides outreach services in minority ethnic communities within London to raise awareness of – and provide information about – autism. However, there are still very few projects or services of this nature in England or Wales. Most of the services that do exist are co-ordinated by the voluntary sector with little support available from statutory services. The Early Support pack, funded by the Department for Education and Skills (DfES)¹⁴, is an extremely useful resource for parents with young children who have

received a diagnosis of autism, but it is not available in any language other than English or in other formats, such as language tapes. There have been many calls for this resource to be made available in community languages but as yet the DfES has not acted upon them.

There are also many reasons why families from minority ethnic families may find it difficult to access generic support for themselves or for their children. Language barriers inhibit some people's understanding of the services to which they are entitled. Other people may not access support due to fear of discrimination or racism, on the basis of personal experiences or on hearsay. In some communities disability and autism are seen as private matters that should be coped with within the family. BME families who took part in our research also mentioned a lack of culturally appropriate services or services that value diversity.

Professionals who work in mainstream services may assume that services are open and accessible to people from all backgrounds and often lack understanding of the additional barriers faced by families from BME backgrounds. As a result, they do not make enough effort to reach out to them and provide the required support. The NAS's BME Communities Project runs autism awareness and cultural awareness training to generic and autism-specific professionals to equip them with the skills and confidence necessary to meet the needs of BME families. This type of innovative project should be funded and rolled out so that families across England and Wales can benefit.

¹⁴ *Early support information for parents. Autistic spectrum disorders (ASDs) and related conditions.* (2006). London: DfES.

Recommendations

- The lack of research about the experiences of families from BME communities in the UK with a child with autism must be filled.
- Research should be commissioned into the impact of cultural heritage on the diagnostic process. This should include investigation of the relationship between children's EAL status and the professional estimation of the nature and severity of their needs.
- Local authorities should monitor the number of children in their area with autism, including their ethnic background, and plan services accordingly.
- Local authorities should develop culturally relevant autism information and outreach for BME communities to increase understanding, reduce the referral delay and support families pre and post diagnosis.
- The DfES should produce and distribute the Early Support pack in community languages and in appropriate formats, such as language tapes.
- Local authorities, Primary Care Trusts (PCTs) and Local Health Boards (LHBs) must ensure that generic autism services are accessible to families from all ethnic backgrounds.





The right school for every child

Children with autism from all communities are individuals and the needs and strengths of one child will not be the same as another. Although the education choices for all families of children with autism are limited, our survey revealed that for families of children from black and minority (BME) communities they are even more limited. Just 31% of parents of BME children felt as if they had a choice of school for their child. This figure compares to 41% of parents of White British children.

"It was a big fight. The school of my choice was rejected, as it was a private school. I lost a tribunal case. The school that my son attends now is a borough residential school. To obtain a place even in this school was a struggle (I had to get Directors of Social Services, Education and the MP involved). The reason for the struggle was residential schools cost more money even though the school meets my son's needs to some extent."

"I feel that I had to learn the law and Government policy and constantly complain and argue about his needs and repeatedly explain what autism is and how it would impact on school life. Education officers' first priority is money rather than what is best for your child. They have an attitude that you should be grateful for what you get. The greatest barrier I experienced was the attitude that 'if the child needs this much support, why are they not going to a special school?'"



Many parents and carers of children with autism talk about having had to fight for an appropriate education for their child. This can be more difficult for some BME families for reasons including language difficulties, lower confidence, limited understanding of the education system, a fear of being ridiculed or perceived as difficult, or a combination of these factors. An evaluation of the special educational needs (SEN) Parent Partnership Services in England¹⁵, statutory services that offer advice, information and support to

parents of children with SEN, revealed that many local authorities offer limited support for parents for whom English is not their first language. Fewer than half of

¹⁵ Rogers, R. et al. (2006). *Evaluation of the special educational needs parent partnership services in England*. Research report RR. Nottingham: DfES.

Parent Partnership Services used community languages in leaflets. Although about two thirds of Parent Partnership Services made translators available, as the authors point out, this does not address the problem of making initial contact with parents who do not have a good understanding of English. This issue can only be addressed by increasing understanding of autism within BME communities and amongst professionals who work for culturally specific outreach services. Local authorities must also respond by providing additional information and support for BME families to help them understand their rights and entitlements and to support them through the statutory process if this becomes necessary.

"Some parents are more active and will push for services for their children. We are not like that; maybe that makes it more difficult for our children."

"It took nearly two years because at his first school they dismissed that there was anything wrong in the first place. The school had many Polish children who couldn't speak English at all (my son was born in the UK) and they claimed it was 'not uncommon for children of foreign parents to have difficulty with reading and writing'. Our son's father is British and was born in the UK. There was no reason for our son to be the worst at reading and writing in his class."



"My experience with the local authority has been one of waiting and fighting."

"If my son could go to the school of my choice, then his potentials may have been better taken care of."

Bullying

41% of children from BME communities in our survey had been bullied, and many parents commented on the devastating impact of bullying on their child's educational progress, relationships and mental health. Because of the nature of the condition, children with autism may not understand the motives of other children or have the social skills to handle difficult situations. This can mean they are easily led or provoked by bullies, which further compounds their difficulties with social communication and interaction.

"My son was bullied at school continually. However, he was the one punished, it was easy for him to be 'set up' and [his] peer group encouraged him to jump out of windows etc. He was told he was 'rude' by staff because of his abrupt manner of speaking and because he 'argued'. Being very intelligent, he often challenged staff and was punished very much with detentions and being shouted at."

"My child has been bullied on a number of occasions. His first school really did not do much until I intervened by writing and requesting the anti-bullying policy. They suggested that the incidents were self-inflicted."

"We've had to leave our old school because my son was bullied there for ten months and came home with horrific bruises and was hysterical in the mornings because he didn't want to go back to that school. At first they recorded the injuries, but explained it away by 'accidents'. But no matter how many times we've complained, they failed to stop the bullying. He told teachers about the bullying nearly every time it happened, but he was either fobbed off or told by the Acting Headmistress that he was lying. After I came to pick him up with blood trickling down his chin (because he was chased and fell hitting his chin on the sharp edge of a low concrete wall), he was hysterical and said the teachers wouldn't listen to him. When I went back to the school, the Headmistress made all sorts of excuses, concluded it was his fault, anyway – he shouldn't have been running (he's only six), then stood over him as he sat down on the floor sucking his thumb and rocking and shouted: 'You're lying, aren't you? You've been making all this up, haven't you?'"

"She gets teased at school. She doesn't communicate this to me at the time."

One parent's quote reveals an experience that we hear from families on a regular basis:

"There has been a threat of exclusion from the current school because he bit a girl who had bullied him."



Because of their communication difficulties, children with autism who are bullied often struggle to explain that bullying has taken place. Out of frustration and the ongoing distress caused particularly by repetitive bullying, they may display challenging behaviour. In many instances, schools respond by excluding the child with autism, without exploring the reasons behind the challenging behaviour, even where it is uncharacteristic. However, there are examples of excellent practice where schools have successfully tackled bullying – be it on

the basis of ethnicity, disability or another reason – and put strategies in place to protect all children. For example, some schools address children's difficulties at lunchtime by organising lunchtime clubs or allowing children with an ASD to go to the library or to use a computer.

Bullying on the basis of disability, race or both is unacceptable and must be addressed by better training for school staff and by ensuring that the interests of children with autism and children from BME backgrounds are explicitly included within schools' anti-bullying policies.

Exclusions

In our survey, 24% of BME children had been excluded from school (compared to 20% for the overall sample). In addition, just 22% of parents who describe themselves as belonging to a minority community said that their local authority provided support when the child was excluded compared to 29% of White British families¹⁶. Data on fixed term exclusions for pupils with SEN in England in 2004-05

reveals substantial variation between ethnic groups, ranging from 11% for Asian pupils at secondary level to nearly 38% for mixed race pupils¹⁷. Further analysis of the reasons for these differences must be prioritised.

“My son missed several years of school, but it was never officially described as exclusion although it was often an implied threat. I fought very hard for the school to recognise that my son was a good child but was very afraid of the school. The school felt there were ‘other issues’ and the educational psychologist report suggested ‘something in his past’.”

“He was once excluded because his one-to-one was off sick when he first started a mixed special needs day school chosen by the local authority. I raised hell and the NAS also helped me with legal points. This was never repeated.”

The disproportionate rate of permanent exclusions for some minority ethnic groups has been highly publicised over recent years and a number of initiatives put in place to address it. The Government, Welsh Assembly Government and local authorities should attach the same seriousness to the rate of exclusion for children with autism from BME backgrounds or else risk the further marginalisation of these vulnerable children, and significant additional costs in finding an alternative placement for them.



Recommendations

- Education choices for all families of children with autism are limited but our survey reveals that the choices for those families from BME communities are even more so. It is essential that local authorities work to ensure that every child with autism has local access to a diverse range of mainstream and specialised educational provision which can meet the child's individual needs.
- Education professionals should raise awareness and provide information and support in a range of community languages and formats to families from BME communities. This information should cover the education system, their rights and entitlements and choosing a school.
- Bullying on the basis of disability, race or both must be addressed by better training for school staff and by ensuring that the interests of children with autism and children from BME backgrounds are explicitly included within schools' anti-bullying policies.
- The Government and Welsh Assembly Government must prioritise analysis of the reasons for differences between ethnic groups in the exclusion rates of children with SEN.

¹⁶ The survey did not cover the reasons for exclusion.

¹⁷ Number of fixed period exclusions by ethnic group and special education needs in maintained primary and secondary schools 2003-04 and 2004-05. Response to a parliamentary question from Janet Dean, MP. Number 110588. 1 February 2007.



The right training for every teacher

With an estimated prevalence rate of 1 in 100 children¹⁸, all schools should expect to teach children with autism and have the understanding, resources and specialist support to do so. At present, teachers do not receive any compulsory autism training and only 31% of black and minority ethnic (BME) families in our survey thought that teachers had received the professional training they need to meet the special needs of children with autism.

The National Autistic Society (NAS) is pleased that the Government has stated that all new special educational needs co-ordinators (SENCOs) in England will receive autism training. However, there is currently no such commitment in Wales and no guarantee that existing SENCOs will receive autism training. The commitment by the Government to produce a teacher pack on autism for all schools in England, a recommendation of the make school make sense campaign, is also welcome. This pack will provide a useful basic resource for teachers with little or no understanding or experience of autism. However, in order to meet their duties under the *Special Educational Needs and Disability Act (SENDA) 2001* and *Disability Discrimination Act (DDA) 1995* and 2005 to ensure that they do not treat disabled pupils 'less favourably' because of their disability, all teachers must receive comprehensive training to help them understand and adjust their approach in working with children with autism.



Our survey reveals that BME families rate the quality of training of all professionals in their child's school at least 10% lower than their White British counterparts. BME families rate whole school understanding of autism as 21% lower than their White British counterparts. Parents from all minority ethnic groups were generally less satisfied with the professional understanding of autism in non ASD-specific environments and particularly at secondary level. The reasons for lower levels of satisfaction with teacher training by BME families are not clear. They may be the result

of language difficulties, lack of understanding of the education system, cultural differences in expectations of teaching staff, or a combination of these factors and others. It is vital that professionals who work with children with autism from minority

¹⁸ The National Autistic Society (2007).

ethnic communities receive training in cultural awareness and its impact on understanding disabilities so that they are able to support children with autism and can adapt the curriculum to meet their needs if required. The Government and Welsh Assembly Government should ensure that initial teacher training and guidance to schools includes information about the potential for some children to be discriminated against on the basis of their disability and their ethnicity.

School staff must also have the skills to engage parents and carers in their child's education. Some schools employ staff to work specifically with children from BME backgrounds and their families. It is important that these workers reach out to children with disabilities, including autism, and share their own expertise with staff throughout the school.

"My son left after two weeks because of the lack of support. He has since returned and explained to the staff what Asperger syndrome is about and help he might need."

"My daughter missed the school dinner bell and locked herself in the loo in distress. The teacher's response was 'You twit, why didn't you ask the dinner lady for help?'"



"I feel the level of ignorance in schools is shameful."

"If one single change was to be made to the teaching and support of my son, it would be to educate the staff and the special needs officers at the local authority who at one stage suggested my son might have a 'chip on his shoulder' about being Black. I fled this meeting in tears and never received the minutes, hardly surprising!"

"All the other children's parents had a meeting with staff before their children started at the school. We never had any of these meetings. No one tells us anything and we are hoping to get some strategies. When they had a parents' evening we asked for an interpreter, but the school did not provide one and I have no idea what was explained."

"At his new school, with all the goodwill in the world, without real training in autism they are not very effective."

As some of the quotes from parents reveal, there are staff and whole schools whose understanding of autism is excellent.

"I am satisfied with the support my child receives because he has a language and communication support assistant who goes in regularly to brief his teaching assistant and teacher on what support to offer. What he does in school is also sent home for him to practise with me and whenever I ask for advice or materials to help my son at home it has always been sent."

“My child’s school has been proactive in gaining support and training for all staff. Not just teaching staff but also support staff from the caretaker to dinner ladies and office staff so all employees at the school are aware of his needs and how to interact with my child.”

“At the moment we have an understanding teacher, but I can’t guarantee that in the future.”

As part of the *make school make sense* campaign, The National Autistic Society launched a ‘*make school make sense* heroes’ initiative where we encouraged young people and their families to nominate individuals who have made a positive difference to their experience at school. The many nominations we received reveal the dedication of individuals from across the UK. However, as one of the quotes in this report illustrates, many parents fear that if they do find an understanding teacher they can’t rely on this level of understanding in the staff that will teach their child in the future. It is vital that good practice becomes standard practice in schools across England and Wales.

Recommendations

- Training in autism should be provided for professionals working with families from BME communities in schools, early years settings, outreach services and other services.
- All professionals in schools should receive cultural awareness training so that they are able to meet the needs of diverse communities.



The right approach in every school



Speech and language therapy (SALT)

SALT is an important intervention for all children with autism, who have difficulty with both verbal and non-verbal communication. However, there can be particular issues in teaching communication to children where English is an additional language, particularly where word order of their first language differs from English. 51% of children from black and minority ethnic (BME) families in our survey receive SALT in some form but a further 28% of parents believe that their children would benefit from SALT but are not able to access it. As has already been discussed, if children for whom English is an additional language do not receive a diagnosis because of their EAL status, they miss out on necessary interventions, including SALT, further disadvantaging their progress at school.

"My daughter needs speech therapy but as the speech therapist is fully booked she will not get this for another year."

Michael's story*

Michael is ten and describes his ethnicity as Ghanaian. He goes to a mixed special school with an autism unit. He likes computers, and looking at street and tube maps.

"My name is Michael and I go to a special school. I go to a school in a car along with two others. The driver comes to pick me up. It can be a bit confusing when I get into the car, as I am never sure where I should be sitting.

At school I have five friends. I like to listen to music with friends. Play cars on the floor. I like playing.

At school we do different things that are on our schedule – ICT, working, choosing, computer, see street maps, lunch, playtime, relaxation, whiteboard, playtime, snack, choosing, dancing and park, and home time. I also do drama with Paula.

At school I have a helper who helps me. She helps me in tying my laces. I like her. I can also ask for help from my teacher.

When I grow up I want to work on Thames tunnel and be an engineer on the Metropolitan line, or East London line."

* Michael is a pseudonym.

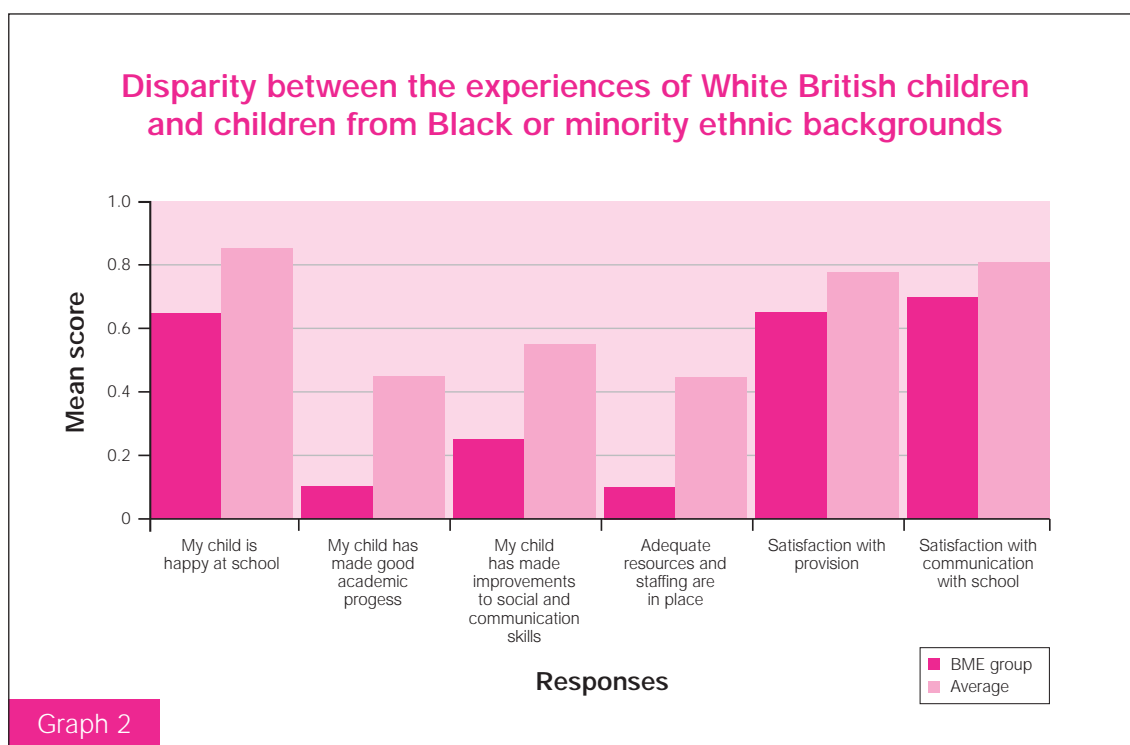


Culturally sensitive and autism-friendly schools

The factors we have addressed in this report – from parental understanding of autism to professionals' cultural awareness when dealing with BME families to the development of appropriate services – are all essential to the cultivation of culturally sensitive autism-friendly environments. Given the issues we have already explored, it will not come as a surprise that

parents from BME communities were significantly less satisfied with their child's academic and social progress compared to their White British counterparts. They were also less satisfied with whether adequate staffing and resources were in place (see graph 2 below).

"I really hope that my daughter gets the same number of hours support in the coming years. The local authority should not deprive children with special needs of help. This is their future and they should be helped."



Recommendations

- Schools and local authorities should monitor the experiences of BME families to assess and address differences in satisfaction levels.
- The Government and Welsh Assembly Government should resource and monitor the implementation of SALT actions in the *National Service Framework for children, young people and maternity services* in England and in Wales and ensure that children from BME backgrounds can and do access this support if they need it.
- Speech and language therapists working with children from bilingual or multilingual families need to be aware of strategies to teach communication skills to these children.

Good practice

Some schools and local authorities already provide excellent support to children with autism from black and minority ethnic (BME) communities. The examples below, and others like them, should be replicated across England and Wales.

Home-school communication

"The bilingual worker at the school has been very helpful. If I don't understand anything that has been written in the communication book, I ring her and she explains it to me in my language."

Parent

"We are aware that students in our school come from diverse backgrounds. Parents of some of these children may have limited English so we send all our letters to the parents in their own community languages. We have got all the regular letters, such as letters regarding Christmas plays, annual reviews and outings, translated into the main languages spoken by the children in our school. This makes it easy for the school staff to send the required letter."

Deputy Head in a special school

"When Anna started in the school we were aware that we were unable to talk to her mother on a regular basis. We felt that her mother was being denied an opportunity just because she speaks Turkish. We arranged a meeting with her using an interpreter. The class teacher, support staff, and the mother have all found the meeting very useful. For the first time the mother had an opportunity to really understand what we are doing in the school, and from our point of view we had a chance to check about Anna's behaviour and needs at home."*

SENCO at a primary school



Raising awareness

A special school in London was aware of the varied needs of the families of children attending the school from different communities. To ensure that all the parents have equal access to their parents' training course and support groups, they use interpreters. They also run a range of groups for parents from different ethnic backgrounds and provide opportunities for networking across the cultures. Their women-only group is popular with the local Somali and Bengali community as well as some White mothers.

"We were aware that the school was not as successful in involving fathers in autism training courses. We organised a couple of training sessions just for fathers which were delivered on a Saturday by two male presenters. This was greatly appreciated by the fathers who had a chance to understand more about the condition."

Teacher in a special school

* Anna is a pseudonym.

Bradford District Care Trust conducted research into understanding of autistic spectrum disorder (ASD) in the local Asian communities. This led to the production of a short video about ASD in the three main local Asian languages and English. The video provides a brief introduction to autism, followed by information about local services. It has proved particularly useful for families who have literacy issues.

Making adjustments

Alex* is a student at a large, local further education college. He has moderate learning difficulties and an ASD that is not formally diagnosed. He is Muslim by religion. At college, Alex has presented a number of behaviours that are deemed inappropriate on campus by college managers. Amongst these is a need to cleanse himself by strip washing several times during the day making use of public toilet cubicles and wash basins on campus.

To address this behaviour, Alex was offered one-to-one support by the NAS. Initially this was provided by female staff members but recently a male Muslim member of staff has been supporting him and this is working well.

In addressing Alex's behaviours on campus, several strategies have been adopted. Alex is still allowed to undertake his ritual cleansing but is directed towards using the larger 'disabled' toilets which have a water supply within the cubicle offering him greater privacy. A TEACCH schedule¹⁹ has been put into place, outlining his day at college and including regular visits to the toilet to enable cleansing to take place – usually prior to the end of a class before other students go to a break or lunch. Alex has also been given short descriptive Social Stories^{TM20} to follow, promoting socially acceptable behaviours on campus. Staff working with Alex will praise him for following both the Social Stories and TEACCH timetable to reinforce acceptable behaviour and boost Alex's self-esteem.

"Alex completed the 'Learning for Life' course successfully, and will be returning to college in the new academic year, on a new course."

Further Education Co-ordinator

"Our primary school is located in the centre of an authority where there is a high percentage of minority ethnic pupils. Over 90% of the children who attend the school are Asian and there are a number of children diagnosed with autism. This, coupled with the communication issues related to English as a second or other language, has challenged the school to look at its systems of communication throughout all classes and within the whole environment. To this end, Boardmaker symbols²¹ are used in the entrance, classrooms and elsewhere. The teachers have welcomed advice from the local authority's special educational needs advisory teachers and have had bespoke training from the SEN teacher with responsibility for ASD support."

* Alex is a pseudonym.

¹⁹ Visual timetables using picture, photographs or words to help the student understand what is expected in a situation and what will happen next.

²⁰ Stories written for a person with autism explaining in words and pictures, step by step, what will happen in situations where they may feel anxious and how they should cope with situations they find difficult.

²¹ A type of visual communication tool.

The communication observed within the classrooms, the use of visual schedules and clear spoken language along with the structure and routine built into the day enable the children on the autistic spectrum and their peers to achieve success. Interventions used to support the needs of children on the autistic spectrum are recognised as good practice for all children and make the school accessible for inclusion."

Teacher at a mainstream primary school in Greater Manchester



Culturally sensitive schools

"We are conscious that as part of religious education we need to give all our students a broad experience so that they feel that their religion is acknowledged by the school. We feel this will help our students to cope with differences which a number of them find difficult. It also helps them to learn the routine for going to their religious place, thereby helping them to be integrated into their community. We organise regular visits to all the religious places in the local area. This has helped the students as some of them are now aware of how to behave in the different religious places, including their own. A number of parents feel confident to take their children to their places of worship now."

Deputy Head

"We organise cultural events showcasing the culture of various parts of the world. This reflects the diversity of the students in our school, and provides them with an opportunity to explore their own culture as well as others. We also try to include this diversity throughout our curriculum. For example, in food and technology we cook food from different parts of the world and not just the traditional English recipes. A number of people believe that children with autism are not aware of their cultural heritage, the response we get from our students when it is food from their communities tells us a different story."

Inclusion officer in a secondary school

Taking responsibility

Schools in one London borough have a big proportion of children from minority ethnic backgrounds. The special educational needs (SEN) department was aware that these numbers were not being reflected in the number of children with an ASD having an SEN statement. The department formed a professional group to investigate any patterns on the basis of ethnicity and social background which need to be addressed to ensure that all families have equal access to get appropriate support for their children with an ASD.



Time to end the double discrimination

Children with autism from black and minority (BME) communities experience discrimination on two fronts – their disability and their ethnicity. This isolates them from the education system that should provide opportunities for success. Some excellent practice exists but sadly it is not widespread. The neglect of BME families by researchers, professionals and service providers is shameful and must be addressed with urgency. Educational provision for all children with autism is inadequate, but for children from BME communities it is even worse. We must *make school make sense* for all children with autism.



About The National Autistic Society (NAS)

The NAS exists to champion the rights and interests of all people with autism and aims to provide individuals with autism and their families with help, support and services that they can readily access, trust and rely upon and which make a positive difference to their lives.

Autism Helpline

Confidential information, advice and support

Open Monday – Friday, 10am – 4pm

Tel: 0845 070 4004

Minicom: 0845 070 4003

Email: autismhelpline@nas.org.uk

Some of our UK-wide services, such as the Autism Helpline, have access to a telephone-based interpreting service. Through this service we can provide information in over 150 languages. However, callers need to speak in English at first to let staff know their name, contact number, and preferred language. After taking these details, we will be able to call you back with an interpreter.

The NAS provides a range of its publications in languages other than English. For details visit www.autism.org.uk/pubs/leaflets and www.autism.org.uk/languages or call 0845 070 4004.

Advocacy for Education Service

The Advocacy for Education Service provides advice and advocacy on special education needs provision and entitlements for families whose children have an autistic spectrum disorder.

Tel: 0845 070 4002

Email: advocacy@nas.org.uk

Website: www.autism.org.uk/advocacy



The National Autistic Society
Head Office
393 City Road
London
EC1V 1NG
Tel: 020 7833 2299
www.autism.org.uk

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ISBN 1-905722-27-3 978-1-905722-27-3

The National Autistic Society is a company limited by guarantee
Registered in England No. 1205298
Registered office: 393 City Road, London EC1V 1NG
Registered as a Charity No 269425